



DEPARTMENT OF HEALTH AND HUMAN SERVICES

Centers for Disease Control and Prevention

[60Day-22-22CL; Docket No. CDC-2022-0021]

Proposed Data Collection Submitted for Public Comment and Recommendations

AGENCY: Centers for Disease Control and Prevention (CDC),
Department of Health and Human Services (HHS).

ACTION: Notice with comment period.

SUMMARY: The Centers for Disease Control and Prevention (CDC), as part of its continuing effort to reduce public burden and maximize the utility of government information, invites the general public and other federal agencies the opportunity to comment on a proposed and/or continuing information collection, as required by the Paperwork Reduction Act of 1995. This notice invites comment on a proposed information collection project titled Population-based Surveillance of Outcomes, Needs, and Well-being of Children and Adolescents with Congenital Heart Defects (CHD). The purpose of this collection is to provide insight into public health questions that remain for CHD and to develop services and allocate resources to improve long-term health and well-being.

DATES: CDC must receive written comments on or before **[INSERT DATE 60 DAYS AFTER DATE OF PUBLICATION IN THE FEDERAL REGISTER]**.

ADDRESSES: You may submit comments, identified by Docket No. CDC-2022-0021 by either of the following methods:

- Federal eRulemaking Portal: Regulations.gov. Follow the instructions for submitting comments.
- Mail: Jeffrey M. Zirger, Information Collection Review Office, Centers for Disease Control and Prevention, 1600 Clifton Road, N.E., MS H21-8, Atlanta, Georgia 30329.

Instructions: All submissions received must include the agency name and Docket Number. CDC will post, without change, all relevant comments to Regulations.gov.

Please note: Submit all comments through the Federal eRulemaking portal (regulations.gov) or by U.S. mail to the address listed above.

FOR FURTHER INFORMATION CONTACT: To request more information on the proposed project or to obtain a copy of the information collection plan and instruments, contact Jeffrey M. Zirger, Information Collection Review Office, Centers for Disease Control and Prevention, 1600 Clifton Road, N.E., MS H21-8, Atlanta, Georgia 30329; phone: 404-639-7570; E-mail: omb@cdc.gov.

SUPPLEMENTARY INFORMATION:

Under the Paperwork Reduction Act of 1995 (PRA) (44 U.S.C. 3501-3520), federal agencies must obtain approval from the Office of Management and Budget (OMB) for each collection of information they conduct or sponsor. In addition, the PRA also requires federal agencies to provide a 60-day notice in the Federal Register concerning each proposed collection of information, including each new proposed collection, each

proposed extension of existing collection of information, and each reinstatement of previously approved information collection before submitting the collection to the OMB for approval. To comply with this requirement, we are publishing this notice of a proposed data collection as described below.

The OMB is particularly interested in comments that will help:

1. Evaluate whether the proposed collection of information is necessary for the proper performance of the functions of the agency, including whether the information will have practical utility;
2. Evaluate the accuracy of the agency's estimate of the burden of the proposed collection of information, including the validity of the methodology and assumptions used;
3. Enhance the quality, utility, and clarity of the information to be collected;
4. Minimize the burden of the collection of information on those who are to respond, including through the use of appropriate automated, electronic, mechanical, or other technological collection techniques or other forms of information technology, e.g., permitting electronic submissions of responses; and
5. Assess information collection costs.

Proposed Project

Population-based Surveillance of Outcomes, Needs, and well-being of Children and Adolescents with Congenital Heart Defects - New

- National Center on Birth Defects and Developmental Disabilities (NCBDDD), Centers for Disease Control and Prevention (CDC).

Background and Brief Description

CHD are the most common type of structural birth defects, affecting approximately one in 110 live-born children. Due to advances in survival, there are approximately one million children with CHD in the United States. With vast declines in mortality from pediatric heart disease over the past 30 years, it is vital to evaluate health, social, educational, and quality of life outcomes beyond infancy and early childhood. However, existing U.S. population-based data are lacking on these outcomes among those born with CHD and the changes that may occur with time and age. U.S. data is needed to provide insight into the public health questions that remain for this population and to develop services and allocate resources to improve long-term health and well-being.

For this project, we will use data from U.S. state birth defect surveillance systems, or population-based studies derived from them, to identify a population-based sample of children and adolescents 2-17 years of age born with CHD. We will then use state databases and online search engines to find current addresses for those individuals and mail surveys to their caregivers inquiring about the child's cardiac and other healthcare utilization, barriers to healthcare, quality of life, social and educational outcomes, and transition of care from

childhood to adulthood, as well as needs and experiences of the caregivers. The information collected from this population-based survey will be used to inform current knowledge, allocate resources, develop services, and, ultimately, improve long-term health of children and adolescents born with CHD.

We estimate receiving completed surveys from 7,667 caregivers of children and adolescents with CHD in the birth defects surveillance systems. To generate sufficient sample size, accounting for non-response, from caregivers up to 17 years after the birth of their child with CHD, we intend to sample 100% of eligible CHD cases identified through select birth defect surveillance systems. The survey takes approximately 20 minutes to complete. Therefore, we estimate the total annual burden to be 2,556 hours. There are no costs to participants other than their time.

Estimated Annualized Burden Hours

Type of Respondents	Form Name	Number of Respondents	Number of Responses per Respondent	Average Burden per Response (in hours)	Total Burden (in hours)
Caregivers of individuals aged 2-17 years with a CHD	Survey questionnaire	7,667	1	20/60	2,556
Total					2,556

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